

The Native American
Women's Health Education
Resource Center

LIVING WITH HIV



**New Tests,
New Treatments**

There is still no cure for AIDS, which is caused by the human immuno-deficiency virus (HIV). However, it is possible for people to live with HIV for years without significant symptoms. Medical advances provide new tools to monitor HIV and new anti-HIV medication which can allow people with HIV and Aids to treat their disease as a long-term manageable condition.



How does HIV work?

People who are HIV positive can show little or no sign of illness for many years. After the initial infection, there is a period in which our immune system effectively defends itself against HIV. HIV survives in the body by invading the immune system's virus-fighting cells (known as T-cells or CD4+ cells), killing them while making more copies of itself. The body then responds by making more CD4+ cells to replace those that are lost in HIV replication. In time, however, HIV overtakes the body's ability to make enough CD4+ cells to fight off other illnesses.

Why are CD4+ cells important?

CD4+ cells help your immune system fight off viruses, including HIV. When HIV lowers a person's CD4+ cell count significantly (usually to under 200) a person is at risk for **opportunistic infections**-- diseases that someone with a healthy immune system could handle, but for someone with HIV are serious, even fatal.

What is “Viral Load”?

Viral load is the quantity of HIV virus that is in the blood. Viral load is measured through a blood test. This information is then used to predict HIV disease progression before it happens, to show how well your treatment is working.

Will this tell me how soon I'll get sick?

Not exactly. Viral load and CD4+ cell counts are used together to give the most accurate picture of where someone is in terms of their HIV. There is still room for individual difference, but overall people with higher viral loads and low CD4+ cell counts are more likely to progress to AIDS.

Should I start treatment as soon as I know that I'm HIV positive?

You should discuss with your doctor whether or not to begin anti-HIV medication. Early therapy has the advantage of preserving immune function by fighting HIV before it has a chance to destroy many CD4+ cells, but the medication itself affects your life as well. Most anti-HIV medications cause side-effects (like nausea, abdominal pain, or fatigue) which can have a big impact on your quality of life. Also, since anti-HIV medications are new, we don't know how well the drugs work over a long period of time or what long-term side-effects they might have. Basically, you need to decide what's right for you.

What if I'm already sick?

The Center for Disease Control (CDC) recommends that all patients diagnosed with advanced HIV disease should be treated regardless of viral load. If you are already showing signs of illness, it is highly recommended that you start treatment immediately.

What kind of treatments are there?

There are three classes of **antiretroviral** therapies, **nucleoside reverse transcriptase inhibitors** (NNRTIs), **non-nucleoside reverse transcriptase inhibitors** (NNRTIs) and **protease inhibitors** (PIs). These drugs do not harm HIV directly, but interfere with the process HIV uses to make more copies of itself. The latest treatments for HIV involve combining two and often three different drugs into a treatment "cocktail." Researchers have found that by combining drugs they can attack the virus in a variety of different ways and at the same time slow its spread and its tendency to become drug resistant.

Combination therapies have shown very promising results, such as lowering viral load to undetectable levels and improving general health and well-being. However, these medications do not work for everyone.

Protease inhibitor warning:

Protease inhibitors, the cornerstone of new combination therapies, have been linked with an increased risk for diabetes. Some HIV-infected patients on protease inhibitors have developed diabetes mellitus or hyperglycemia or have experienced worsening of pre-existing diabetes.

Aren't these treatments expensive?

Combination therapy can range between \$12,000-\$15,000 a year. Indian Health Service does not have a comprehensive program to provide antiretroviral medication, though some facilities (such as those serving the Navajo and Pueblo nations) have special programs to purchase the medications for their patients. Those without special programs must take the funds from their general budget, which is limited. Fortunately, there are some other programs which can assist with access to these medications.

People with HIV/AIDS may qualify for disability benefits from Social Security, which can provide assistance with medication if you then qualify for Medicaid. The AIDS Drug Assistance Program, under the Ryan White CARE Act,

was designed to provide medications to low-income individuals with HIV. As the states have authority to establish income and medical eligibility criteria and to determine how these drugs will be purchased and distributed, these programs vary considerably from state to state. Some drug companies have programs to help people with low-income access their medications. If you are in an urban area, you might also want to consider participation in a clinical trial (which then provides free experimental drugs). For more information, contact the



AIDS Clinical Trials Information Service at
1-800-TRIALS-A.

How can I tell if my therapy is working?

An effective therapy should reduce viral load to undetectable levels within six months. After you begin therapy, you should keep getting viral load and CD4+ counts done every 3-4 months.

Treatment can fail for many reasons. The virus could be resistant (unresponsive) to the drug, your body could be inefficiently processing the drug, or you may have taken breaks from your medication schedule.

Your doctor needs to tell you about all of the potential side-effects, drug interactions, dietary requirements, and the possible need to alter other medications for best results.



What can I do to prevent drug resistance?

To prevent drug resistance, you should:

- ☐ Avoid monotherapy (being on only one drug)
- ☐ Avoid drug holidays. When you stop taking parts or all of your therapy, it gives the HIV in your body a chance to build up resistance to the medication. Adhering to your drug regimen is crucial.

- ☐ Learn as much as you can about possible interactions with your combination therapy and any other medications you may be taking.
- ☐ See your doctor at the first sign of severe diarrhea, since diarrhea decreases the amount of medication available to fight HIV in your body.

Is antiretroviral therapy the only kind of therapy I need?

No! You still need to worry about the prevention of opportunistic infections. Opportunistic infections (or OIs) are infections or conditions that take place when the immune system is weakened. In order to prevent OIs you may need to take medicines to prevent or delay some infections, such as PCP pneumonia. **Prophylaxis** (preventative therapy) for OIs can be used to prevent a first infection or, more commonly, to prevent infections from returning. As with the antiretroviral drugs, consistently taking your medication is crucial. If you skip doses or take “drug holidays” you can become vulnerable to resistant or more serious OIs.

To properly fight OIs, it is important that you learn to monitor your health. Go to a clinic or a doctor for regular check-ups and watch for signs of infection, reporting them immediately. You may want to be tested regularly for tuberculosis (TB), as people with HIV are at special risk. HIV-positive women should also have regular pelvic exams. In general, learn as much as you can about how to keep healthy!



For More Information:

Contact your local IHS facility and/or state health department to learn more about treatment, drug assistance programs (including how to access Ryan White CARE Act Programs), and AIDS Service Organizations in your area.

CDC National AIDS Clearinghouse:
1-800-458-5231

National AIDS Hotline:
1-800-342-2437

HIV/AIDS Treatment Information
Service: 1-800-HIV-0440

Teen AIDS Hotline:
1-800-440-TEEN

National Native American AIDS
Prevention Center (NNAAPC)
134 Linden St.
Oakland, CA 94607
Phone: (510) 444-2051
Fax: (510) 444-1593

and

The Native American Women's
Health Education Resource Center
P.O. Box 572



Lake Andes, SD 57356
Tel: (605) 487-7072
Fax: (605) 487-7964
www.nativeshop.org

Prepared by Rebecca Nagel